



Peter

Peter's primary school years were a nightmare and his behaviour at home took a toll on his whole family. Lack of support and fighting the authorities added to the burden. Eventually his parents made the heart-breaking decision to request a residential placement for Peter. With experienced support staff who all have PDA training and make appropriate adjustments, Peter went on to thrive in this environment and now aged 22 is leading a happy and fulfilling life. Post-18 provision has been a further minefield for the family to negotiate.

Peter is our third child, and from the moment he was born I knew there were underlying difficulties. He never slept for more than 20 minutes at a time, day or night, until he was three and his development was delayed across the board. My sons were both diagnosed on the same day by a community paediatrician – Peter aged 4 with autism and his big brother aged 7 with Asperger's. Whilst I was relieved to have some explanation for their challenges, I wasn't given any information, support or advice. I also queried Peter's diagnosis since I had understood that children with autism had difficulties with imagination, whereas Peter thought he was a fox for most of the day!

Despite him having 1:1 support for half of his nursery week, he was only granted 5 hours support a week on starting school. Peter's first three years at school with nothing short of a nightmare. He would frequently wander out of school and be returned by members of the public, once even hiding in the back of a delivery van! Break times were especially difficult – Peter would often be aggressive to other children and damage property or refuse to return to class unless his big sister (who was only 9) went to fetch him (which in turn had a detrimental impact on her wellbeing).

We had to fight for a statement of special educational needs but eventually secured one in year 3; because the Local Authority felt that he had moderate learning difficulties Peter was moved to an MLD school. Whilst the staff there were lovely and tried every ASD strategy in the book, they weren't able to manage his complex and challenging behaviour either. But they were the first to flag PDA as a possibility. This was a major turning point for us, not least because we now realised that we weren't bad parents it's that we were using the wrong strategies!

We moved Peter to a specialist ASD school with knowledge and experience of PDA, and set about informing ourselves as best we could – this was in 2004, so information about PDA was thin on the ground. The most helpful information came through other parents in the

PDA contact group (the precursor to the PDA Society). Four different paediatricians refused to reassess our son, and in fact seemed quite angry at the mention of PDA. Peter became increasingly avoidant at school, refusing to engage with over half the curriculum and spending much of his day hiding on the toilet. His academic levels stagnated for 3 years despite his teacher describing him as one of the most intelligent children in the school. All our requests for further assessment and support were refused.

In the meantime, home life was becoming increasingly difficult for all of us. Our daughter became very ill with anxiety, depression and panic attacks, had a year off college and was on medication. Our eldest son with Asperger's had an emotional breakdown at 12 (he had hated school since age 8 and had been refusing since age 10), eventually we secured him a Statement of SEN and 20 hours per week home tuition until he went to college at 16. We'd long since stopped trying to go anywhere as a family - one of us would stay at home with one or two children whilst the other parent would take a child to get shoes, clothes or play at the park. We also stopped going on holiday as a family when Peter was 8, there were far too many difficulties, meltdowns and breakages. Our two sons hated each other and frequently tried to kill each other by strangulation, beating or using blunt instruments (all ornaments, mirrors and sharp implements were locked away).

When you have one child whose condition and behaviours are making everyone else in the household mentally, emotionally or physically ill, you feel you need to make a decision before it is too late, even though you know that decision will break your heart. Our decision was to take the Local Authority to tribunal to request a residential placement for Peter. This was a lengthy and costly process. We paid for many independent assessments, and discovered that Peter didn't have moderate learning difficulties but did have many specific difficulties such as Dyspraxia, Dyslexia, Dyscalculia, Memory Recall Difficulties, Severe Emotional Regulation Problems, Language Processing Difficulties and Sensory Processing Difficulties, to name a few! I went to look at twenty six different schools to try and find a suitable placement. After six months the LA conceded the week before the tribunal date, and Peter was awarded a place at a residential school for children with ASD and challenging behaviour.

Within just a few months, we began to see changes in our son that were so positive we knew we had made the right decision for him and our family: because he saw a psychologist every week his emotional regulation began to improve; he was in class every day and finally learning to read; he was having lessons that he was interested in and so he wanted to learn; when he came home at weekends and holidays he was less physically aggressive.

As Peter reached the end of his school life we began to meet with the LA regularly to discuss his future. The LA wanted him to return to our county and go into Supported Living with 3 other young people; they also made it clear that they didn't want to fund any further education even though he had an Education Health Care Plan which should have allowed him to have education or training until age 25. We felt that because our son had only been given the opportunity to start learning at age 14, he should transfer to a Residential Specialist College to continue the great work his school had started. The LA informed us that we had no 'Parental Rights' when Peter turned 18 and that they would make decisions on his behalf, this is known as 'Best Interest' decisions. These words still haunt me today! So we took on a SEN solicitor, who wrote to the LA and eventually we secured our son a two year placement at a specialist residential college.

Peter thrived at the college, loving the practical lessons and courses including wood work, cycle maintenance, the gym and his work experience in an IT office. His life became less about coping with demands to attend lessons he found difficult and become much more fulfilling by being able to engage in things he loved. His behaviour improved significantly. Once again, however, at the end of the two year period we had to appeal to tribunal – the LA again wanted him in 'supported living' and we wanted him to continue at the college. The LA conceded and he has been at the college for a further 2 years.

Peter is now 22 and this will be his final year there. He has even begun a ‘supported work placement’ which he loves because it involves recycling IT equipment (taking machines to pieces to see how they work!) which he has loved doing since he was two years old. He even says he wants to work 5 days a week! Peter has achieved so much in the last eight years, much more than we ever thought possible. We know that most of his achievements are down to the very well trained and experienced staff that manage his behaviour so well 24/7, the environment that he is in and the very flexible management he has received. We are also very aware that without such support and accommodations, things could deteriorate rapidly.

My main message to other parents is to prepare well before your child reaches 18. Securing an accurate diagnosis, an EHC Plan and a school/college placement that can meet your child’s needs is essential. Our children may appear to have ‘mental capacity’ to make their own decisions, but in reality many don’t and will need their parents to help them through the minefield of life for many more years. Far too often I have heard of young people with PDA aged between 18 and 25 being arrested and facing the Criminal Justice System, being sectioned under the Mental Health Act and remaining in psychiatric hospitals for years or taking their own lives due to depression or not being able to face the future. EHCPs can legally last until a young person is 25 years old, though many local authorities will try to cease education and training as soon after a child reaches 18 as possible. It’s essential for parents to know their child’s rights and find out what post-18 provisions there are in their area.

Looking ahead, we’re hopeful that Peter will be able to lead a happy life and fulfil his potential. As a family we have been through very difficult times indeed and have had many battles with the authorities along the way, but we now have three children who are thriving, a Dad who no longer gets called home from work early every other day and a Mum who no longer dreads the future.